

COMMONLY UNDER-RECOGNIZED HEALTH PROBLEMS

(Adapted from Tyler, C.V. (1999) Medical Issues for Adults with Mental Retardation. High Tide Press, Homewood, Illinois.)

Gastrointestinal Problems: Dysphagia, esophagitis, constipation, bowel impaction, gastroesophageal reflux disease (GERD)

Sensory Impairments: Visual and Auditory

Chronic/Recurrent Infections: Most commonly sinusitis and otitis media.

Oral Disease: Infected teeth, periodontal disease. Referred pain may affect behavior or function.

Respiratory Diseases: Chronic obstructive pulmonary diseases (COPD).

Musculoskeletal Conditions: Degenerative joint disease, osteoporosis. Long-term polypharmacy may contribute to these conditions.

Neurological Conditions: Compressive neuropathies from contractures or use of walkers. seizure disorders.

Approximately 30% of adults with MR/DD have syndromes and unique health problems requiring additional screening.

DOWN SYNDROME

Hearing concerns (up to 50%), ocular problems (up to 50%), hypothyroidism (15%), seizure disorders (5-10%), atlantoaxial instability (10%), premature dementia (increased rate), other musculoskeletal problems.

CEREBRAL PALSY

Strength and ROM should be monitored regularly. Particular attention to areas of swallowing, bowel and bladder function in people who are not independent for mobility.

OTHER SYNDROMES

Clinicians are advised to gather necessary information regarding health issues for syndromes that are known to be associated with an individual.

OTHER SOURCES OF INFORMATION

General Internet Resources:

Developmental Disabilities: Resources for Health Care Providers

<http://www.ddhealthinfo.org/>

Family Village <http://www.familyvillage.wisc.edu>

Alliance of Genetic Support Groups
<http://www.geneticalliance.org>

National Organization for Rare Disorders
<http://www.rarediseases.org>

Resources For Specific Conditions: *In addition to the general sites listed above, many organizations created for individuals with specific conditions disseminate and publish their own valuable health related materials.*

Health Care Guidelines for Individuals with Down Syndrome
<http://www.downsyn.com/guidelines/healthcare.html>

National Fragile X Foundation
<http://www.fragilex.org/html/intervention.htm>

Prader-Willi Syndrome Association
<http://www.pwsausa.org/support/medalert.htm>

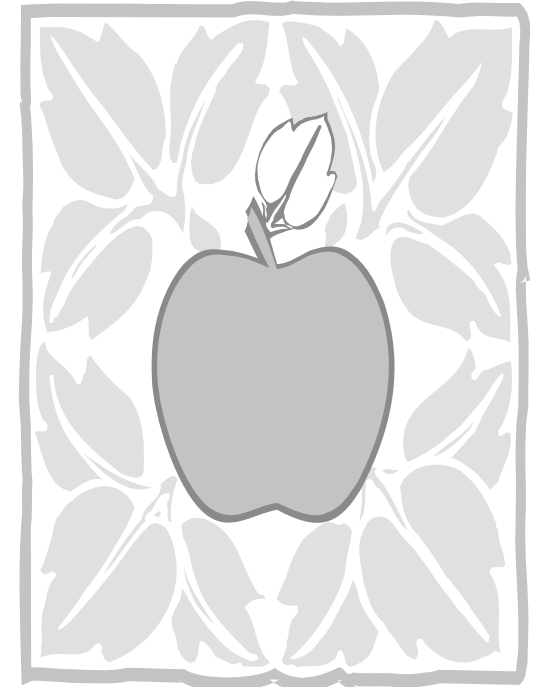
Massachusetts Department of Mental Retardation *Site includes sample forms to be used to help identify medical concerns.*
<http://mass.gov/dmr>



Brochure compiled by the Center for Developmental Disabilities Evaluation and Research/ UMass Medical School for the Massachusetts Department of Mental Retardation
May 2002 (Revised 10/05, 9/07)

PREVENTIVE HEALTH RECOMMENDATIONS FOR ADULTS WITH MENTAL RETARDATION

Guidelines for community practitioners



Distributed by the Massachusetts Department of Mental Retardation

THE PERIODIC HEALTH REVIEW

This brochure was designed to assist the clinician and other caregivers in assuring quality preventive health care to adults with mental retardation. Many adults with mental retardation are involved in their own health care and are able to make decisions regarding their own health. The following suggestions may assist the clinician in supporting persons with mental retardation and improve any health care encounter.

PREPARATION

Many adults can be helped to feel more comfortable at a medical visit if they feel adequately prepared for the event. Family, or support staff can be encouraged to introduce unfamiliar items such as a stethoscope or a blood pressure cuff at home to allow the instrument to become more familiar and facilitate cooperation during an exam.

During the exam, it is helpful to prepare patients for procedures by explaining them well or allowing patients with sensory impairments to explore the instruments that are about to be used. Performing simple examinations in an office or quiet waiting room may reduce a person's anxiety.

If someone is particularly anxious or an invasive screening procedure is necessary, the clinician might consider sedation prior to the appointment. In some cases, multiple procedures can be performed while the patient is sedated (dental work, or routine blood work, for example) to reduce the number of times a person is exposed to the risks of sedation.

COMMUNICATION

First direct your questions to the patient to determine their own perception of their health status and needs. If communication is a problem, clinicians may have to rely on a family member or support staff to provide information relating to signs or symptoms of health concerns. Questions regarding changes in the individual's behavior and adaptive function can bring underlying physical and mental health issues to light.

ADULT PREVENTIVE CARE RECOMMENDATIONS

Based on Massachusetts Health Quality Partnership (MHQP) Adult Preventive Care Recommendations 2005 <http://www.mhqp.org/>
Guidelines and discussion of risk factors are for the general population. Modifications to meet the health concerns of the population with mental retardation are below. Risk factors remain the same as the general population unless specified.

PROCEDURE	RECOMMENDATION FOR ADULTS WITH MENTAL RETARDATION
Health Maintenance Visit	Recommend Annually for all age groups, includes medical history, preventive screenings and physical exam.
CANCER SCREENING	
Mammography	Follow MHQP recommendation. If procedure is difficult to complete for behavioral or physical reasons, recommend every two years when annually was recommended.
Pap Smear	Every 1-3 years starting by age 21 at physician discretion. Risk factors outlined in MHQP standards. Women will likely need considerable preparation for examination. For women who will require conscious sedation or general anesthesia : <ul style="list-style-type: none">• If unlikely to have been sexually active, withhold testing until other invasive testing done.• For women with prior sexual activity, every 1-3 years depending on risk factors.
Colorectal Cancer Screen	Annual fecal occult blood testing recommended beginning at 50 unless high risk. If endoscopy considered important, recommend colonoscopy if need for general anesthesia is likely. For high risk clients, follow MHQP recommendations.
Prostate Cancer Screen	Digital Rectal Exam (DRE) for age 50 (40+ if at high risk). PSA at physician/patient discretion.
Skin Cancer Screen	Periodic total skin every 3 years at age 20-39, annually beginning at age 40 for all skin tones and colors.
OTHER RECOMMENDED SCREENING	
Body Mass Index (BMI)	Screen using CDC BMI standards. If BMI>30kg/m2 offer more focused evaluation and weight loss program.
Hypertension	Recommended at every acute and non-acute medical encounter and at least annually..
Cholesterol	Five year intervals or at physician discretion.
Diabetes (Type II)	Minimum five year testing interval for people under 45 years. Over 45 years old, test every 3 years.
Osteoporosis	Consider risks of medications and in all patients with hypothyroid, mobility impairments. Screen as appropriate.
INFECTIOUS DISEASE SCREENING	
Chlamydia and STDs	Screen annually if at risk.
HIV	Periodic testing of individuals defined as increased risk .
Hepatitis B and C	Periodic testing of individuals if risk factors are present.
Tuberculosis	Skin testing performed on individuals with risk factors every 1-2 years according to MHQP standards.
SENSORY SCREENING	
Glaucoma	At least every 3-5 years. More frequent with risk factors. Screening likely to be more successful using Tonopen.
Hearing and Vision	Careful history regarding observed changes in behavior. Screen annually when possible.
MENTAL AND BEHAVIORAL HEALTH	
Depression	Recommend screening for sleep, appetite disturbances, weight loss, general agitation. Ask questions appropriate to developmental level with less emphasis on subjective verbal explanations of internal states.
Dementia	In persons with Down Syndrome, recommend annual screening for dementia beginning at age 40
GENERAL COUNSELING AND GUIDANCE	
Recommend appropriate counseling to individual and support staff about healthy lifestyle at annual visit and acute visits. Annually counsel caregivers on ways to prevent household injuries (fall prevention, choking prevention, fire/burn prevention). On all visits be alert to behavioral signs of abuse or neglect. Routinely ask patients direct questions about abuse including sexual abuse. Sexuality counseling should include genetic counseling, assessment and discussion of parenting capability as well as folic acid supplementation as appropriate.	